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The Portuguese National Health Service and the Patient Health Information Workgroup

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Abstract

Introduction: The Grupo de Trabalho de Informação ao Utente (Patient Health Information Workgroup) was established under the CAIC - Comissão de Acompanhamento da Informatização Clínica (Monitoring Committee of the Clinical Information Technology) of the SPMS - Serviços Partilhados do Ministério da Saúde (Shared Services for Health Ministry) in order to meet the challenges of new models of management and governance centered on citizens. This workgroup is grounded on the national information campaign named as *"Health Information. More Transparency, Better Decision"*, a project of the Associação Fazedores da Mudança (The Change Makers Association) with financial support of Fundação Calouste Gulbenkian (Calouste Gulbenkian Foundation).
Objectives: To promote discussion topics and present concrete proposals, centered on patients, primarily related with: access to certified, reliable and useful health information; communication strategies; services to be made available on the Patient's Portal/website.
Methodology: A multidisciplinary and inter-institutional group has been constituted with physicians, nurses, sociologists, social workers, health librarians, human resource managers, lawyers and IT experts. The mission is to design and implement an action plan until December 2016.
To the design of the action plan, five main axes were identified: To Know, To Listen, To Improve, To Inform and To Evaluate. Based on a worksheet created for this purpose, the multidisciplinary group identified some actions/tasks to be undertaken. As a result of all the contributions made, a possible and feasible Action Plan was created, supported by some validation criteria: to be aggregator of the presented ideas, to be mobilizers, to enhance multiplier effects, to be impactful, to be structural for future work, to enhancing participation, making awareness and calling for change.
Results: Attempting on this action plan that integrates 5 major initiatives underway at a national level, we intend to achieve the following results based on multiple participatory processes, such as: i) the presentation of the resulting recommendations to the Parliament in order to change the legal framework that regulates access to health information; ii) the identification of useful information for patients; iii) the development of a program consistent of concrete action proposals centered on the patient, for more information, more transparency and better access.
This paper aims to present the project and the results already achieved with its implementation.

Keywords*: Consumer Health Information; Health Communication; National Health Programs; Access to Information; Health Information Management; Civil Rights.*

Introduction

The Patients' Workgroup was created in the scope of the Monitoring Committee for Clinical Informatics (CAIC) of the Shared Services of the Portuguese Ministry of Health (SPMS), with the purpose of making proposals focused on Patients/Citizen's needs.
The citizen is seen as the core of the National Health System (NHS), the framework through which the entire production of information and its access should be refocused.
The more involved patients/citizens are, in a conscious and informed manner, this emphasizes their ability as decision makers, concerning health condition, and influence on the development of health system meant to be as closest to their needs and interests towards health promotion and disease management.
Citizenship, involvement, health literacy, information and semantics are key-concepts of this workgroup.

Objectives

This Patients' Workgroup aims to promote the debate and establish priority actions focusing on patients/citizens, mainly related to:

- Access and production of useful, comprehensive and reliable information;
- Communication strategies of information;
- Services and resources available to enable access.

Methods

Our methodology is based on active listening, appealing to the participation of the several groups and interests involved in this process. Our plan is structured around five areas of action: to know, to listen, to inform and to evaluate, in which we consider a set of initiatives, underlining:

- Health Information: Focus groups for active listening of Patients/Citizens;
- Health Information and NHS: Online Survey;
- National Initiative;
- Concrete proposals for + Capacitation + Access to Health Information.

We underline that the plan of action of this workgroup is mainly guided by the development of frameworks that bind ideas for action, involving patients/citizens, with impact and strengthening the compromise of participation, awareness, an active citizenship towards change.

Results "in Progress"

Currently, the Patient's Workgroup is developing five different initiatives in order to accomplish the main objectives of the project (Figure 1):

INITIATIVE 1	**National Initiative**
INITIATIVE 2	**Thematic Talks Circle**
INITIATIVE 3	**Health Information: Which? Where? For Whom? What For?**
INITIATIVE 4	**+ Capacitation + Access to Health Information**
INITIATIVE Transversal	**Dissemination, Monitoring and Evaluation**

Figure 1. Patient's Workgroup main initiatives.

From the planned actions, we would like to highlight the following:

Dates	Actions
April and May	**Users/Citizen's interviews: Workshops and Online Survey**
May	**Users/Citizen's interviews: Online Survey**
June	**National Initiative**
June and July	**Summary Papers on:** **a) Information Health Ecosystem;** **b) Brief theoretical framework of key concepts;** **c) National and international governmental projects in health information, citizenship and health literacy;** **d) European guidelines and perceptions on the matter;**
July	**Presentation of Guideline Matrix for production and sharing of information on digital platforms (recommendations);**

Figure 2. Patient's Workgroup Action Plan (until July 2016)

Conclusions

At this moment it's not possible to present the final results of this actions once they are still being developed.
However, we would like to state that this Workgroup it's already by itself and for its organization an evidence that we are all co-responsible by the individual and collective health as well as the establishment of dialogue and action bridges between different actors in the health system, including all citizens.
At the end, all we wish for is a more and well informed citizens regarding health information access knowing the existing resources, contexts and developing a global awareness, becoming more active and participative in all this procedures.